# Adapting Health Education Material for Deaf Audiences

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***Problem:*** The deaf population is an often-overlooked limited English proficiency (LEP) group at risk for health disparities associated with low health literacy. Lack of access to health information conveyed via radio, television, or ambient auditory sources such as public conversation further aggravates this population's low health literacy. Methods of adapting health education material for hearing LEP populations do not reach deaf audiences with equal effectiveness. ***Method:*** We adapt health education material for deaf audiences by first determining the "learning points" contained in vetted source material. A dialog-based film script covering those learning points is created. Supplemental content addressing common deaf population knowledge gaps and sociocultural experiences is added. Deaf actors are filmed following the adapted American Sign Language (ASL) script. Their ASL is back-translated into English to yield vocal track and subtitle scripts. The source material author(s) are consulted throughout the process to assure the film's adherence to the learning point list. ***Results:*** Users report that the adapted product is more relevant, engaging, and effective for deaf audiences. ***Conclusion:*** This adaptation approach may aid in reducing deaf population health disparities.

*Keywords:* deaf, health literacy, health disparities, American Sign Language, health education

Health disparities between U.S. populations fluent in the English language and those with limited English proficiency (LEP) are receiving increased attention in research and public policy (Nasir & Nasir, 2006; Nielsen-Bohlman, Panzer, & Kindig, 2004; Schlichting et al., 2007; Snowden, Masland, & Guerrero, 2007; U.S. Department of Health and Human Services, 1999; Youdelman & Perkins, 2005). Studies have demonstrated that language and literacy barriers contribute to health disparities in LEP populations (Ngo-Metzger et al., 2007; Smedley, Stith, & Nelson, 2002; Wilson, Chen, Grumbach, Wang, & Fernandex, 2005).

Deaf people comprise a unique LEP population in the United States, with many of the same barriers to health literacy (Nielsen-Bohlman et al., 2004) and risks for health disparities as hearing LEP populations. Approximately 4.8 million Americans reported being unable to hear or understand speech (Ries, 1994). Similar to hearing LEP groups, the deaf population manifests low English literacy rates. The average deaf high school graduate in the United Stares reads at the fourth-grade level (Holt, Hotto, & Cole, 1994). Lack of access to radio, movie and TV soundtracks, and ambient sources of information, including overheard conversation, deepens and reinforces the *fund of information* deficit (Pollard, 1998) associated with low English literacy in the deaf population (O'Hearn & Pollard, 2008). A substantive portion of the deaf population uses American Sign Language (ASL) as their primary mode of communication (Mitchell, Young, Bachleda & Karchmer, 2006). ASL is a language that is structurally very different from English (Valli, Lucas, & Mulrooney, 2005). As well, many deaf people, in particular those whose primary language is ASL, share a unique set of values, social behaviors, and other characteristics recognized as Deaf[1] culture (Ladd, 2003; Padden, 1980; Padden & Humphries, 1988). These literacy, fund of information, language, and minority cultural characteristics combine to yield a sizable American minority population at clear risk for health disparities but one whose health status has been the subject of very little research or preventative intervention.

The deaf population is at least as much in need of accessible health education information as other American LEP populations. The development of health education material for deaf people must take into consideration English literacy, ASL usage, Deaf socio-

[1] In keeping with preferences in the deafness field, the uppercase "D" will be used when referring to this specific sociocultural group and the lowercase "d" when a more general reference to hearing loss is intended. Although acknowledging the Deaf community's heterogeneity, the term is generally understood as referring to persons who have hearing loss in the severe to profound range, communicate in ASL, and otherwise demonstrate a sociocultural association with the American Deaf community.

cultural characteristics, and fund of information deficits. The purpose of this paper is to describe our method for creating such material and explain why alternative methods may fail to reach deaf audiences effectively.

In the next section, we discuss various methods of creating health education material for LEP populations generally and present opinions on the utility of these methods for deaf, ASL-using individuals. Subsequently, we detail our preferred approach to adapting health education material for this underserved minority population. Specifically, our approach involves adaptation of source material that goes beyond mere translation of the material, encompassing additional modifications in response to deaf population fund of information needs and preferences for learning through dialogic interaction.

## Creating Health Education Material for LEP Populations

One approach to reducing the negative health consequences of English literacy barriers in this country is translation of English language health education material into foreign languages used by U.S. minority populations. Another approach that has been taken is developing health education material "from scratch" for specific LEP populations (Refugee Health Information Network, 2007; U.S. Committee for Refugees and Immigrants, 2008). Each of these methods has advantages and disadvantages.

Translation seeks to bridge language differences between the source material's intended audience and the translated material's intended audience. However, translation is a complex task (Hutchins, 2001; Nasir & Nasir, 2006), especially the translation of medical information (Txabarriaga, 2008), and often falls short of a fully satisfactory outcome (Contreras, García-Alonso, Echenique, & Daye-Contreras, 1999). One strength of the translation approach to reducing literacy-related health disparity risks is that the material chosen for translation could be health education material that, through research, evaluation, or peer review, has been shown to be comprehensive, current, and effective in promoting consumer learning. However, even when skilled translation yields material that, in the target language, remains adherent to the source material, translation alone does not bridge cultural, social, and life experience differences that frequently exist between the source material's target audience and the translated material's target audience (Williamson, Steechi, Allen & Coppens, 1997). Addressing such nonlinguistic differences between the source and target audiences usually requires deviating from the content of the source material in significant ways, which may include changing, adding to, and/or deleting portions of the original content. When the desire for strict adherence to the source material's content (and perhaps even its structure) yields translated material that the target audience can read (or hear) but not fully comprehend or relate to due to differing cultural characteristics or life experiences, the material may fail to effectively impart the learning it was intended to. Yet, when source material has been deliberately selected because of its known value in promoting a desired learning effect, there is risk in deviating from its content, lest its demonstrated effectiveness be diminished or called into question.

A mirror-image mix of advantages and disadvantages results when health education material is developed from scratch for populations who use languages other than English. In this approach, the unique language, cultural, and life experiences of the target population are taken into consideration throughout the planning, writing, illustration, recording, or other steps in creating the learning material. Although linguistic and sociocultural relevance to the target population is maximized through this approach, the tailor-made content means that such material is, to varying degrees, dissimilar to gold standards created in English and endorsed or otherwise vetted by researchers or other health education professionals. Further, such material usually is created by educators or human service providers with pressing needs to employ it with their service population. This imperative, in addition to budget limitations and differing priorities around research, often results in such material not being subject to rigorous evaluation of educational effectiveness.

Another approach to the development of health education material for LEP populations is a mixture of the above two methods. Here, one or more pre-existing (English) materials known to be valid and effective in health education are used as the initial information source. Subsequently, a combination of translation and cultural adaptation is employed, with the goal of yielding a product that conveys the same information as the source material but in ways that include content variations—linguistic, cultural, social, and otherwise—intended to maximize the clarity and relevance of the resulting material for the intended target audience. We will refer to this approach as yielding an adaptation of the source material rather than a translation of it. Regarding this type of adaptation of an HIV education curriculum for Spanish speakers, Devieux, Malow, Rosenberg, Jean-Gilles, Samuels, and Ergon-Perez (2005) noted, "The process of cultural adaptation is a painstaking one that involves ensuring fidelity to the original intent of the intervention and maintaining the nuances of language, both formal and informal" (p. 84). Ideally, the adaptation approach strives to reap the main advantage of the translation approach—adherence to the content of validated, effective source material—as well as the main advantage of the "from scratch" approach that maximizes audience comprehension, interest, and engagement with the material by judiciously modifying that content in light of the intended audience's unique cultural, social, and life experience characteristics.

## Challenges in Deaf Access to Health Education Material

English language soundtracks on health education audio or audiovisual source materials (recordings, radio programs, podcasts, television programs, movies, DVDs, videotapes, etc.) obviously are not accessible to deaf people. Adding captions (English subtitles) to audiovisual media or providing a written English transcript of audio or audiovisual material not only may fail to deliver the information with the same cognitive and emotional impact that a soundtrack yields for those who can hear, the requirement of English literacy to comprehend subtitles or scripts is a barrier to much of the deaf population. Further, subtitles and scripts that follow the English soundtrack faithfully do not allow for accommodations regarding the fund of information needs and sociocultural characteristics of the average deaf individual.

Written health education material designed for low-literacy readers (e.g., Channing Bete, 2008; Children's Health Fund, 2007; Migrant Clinicians Network, 2008) likely provides greater access to deaf individuals than material that has not been modified in this way but the reading strategies and English syntax knowledge

patterns of deaf individuals differ from those of hearing individuals (Engen & Engen, 1983; Transler, Leybaert, & Gombert, 1999), suggesting that literacy-level modification alone is insufficient for reaching deaf readers effectively. Pollard and Barnett (2009) collected data from a sample of well-educated deaf adults who reported much less familiarity with the meaning of vocabulary presented on a list of health-related English words in comparison to hearing comprehension norms. Beyond access to written English itself, literacy-level modification does not address fund of information differences between hearing and deaf readers nor sociocultural differences that may impact deaf readers' comprehension and retention of the material.

A limited number of health education products have been developed for deaf audiences using the from scratch approach described above. Some of these materials are in written form, virtually always heavily illustrated (e.g., Burgess, Shaw, Larew, Oellette & Long, n.d.; Repas, Roberts, Gramly, Cole, & Kunz, 1982; Walters, 2004). Some are filmed materials in ASL (e.g., Missouri Department of Health and Senior Services, n.d.; Pollard, 2003), often with accompanying English captions or subtitles. Some employ a multimedia combination of English text and ASL film segments (e.g., League for the Hard of Hearing, 1996). An increasing number of health education videos in ASL can be found on the Internet (e.g., Advocate Health Care, 2008; DeafDOC, 2006; DeafMD, 2008; University of California, San Diego, n.d.; U.S. Department of Agriculture, 2008). Most of these videos strive to address deaf population fund of information gaps as well as English literacy and/or ASL needs but they are not based on pre-existing health education material known to be effective with hearing audiences. In addition, the effectiveness of such materials in imparting the desired health knowledge or on influencing health behavior change is unknown.

Although it would be possible to translate English language material with proven health education efficacy into ASL, translation alone entails the drawbacks noted earlier, namely, imperfect meaning equivalence and lack of potentially beneficial alterations in light of cultural, social, and life experience differences. Further, in regard to the deaf population in particular, translation alone would not address the crucial matter of fund of information differences between the average deaf person and the average hearing person for whom the source material was intended. English language source material also frequently contains dominant (hearing) culture metaphors, idioms, and jargon that either cannot be translated into ASL or is not familiar or relevant to Deaf audiences (Glickman & Gulati, 2003; Isenberg, 1996; O'Hearn & Pollard, 2008).

In addition, unlike the English language, ASL is a dialogic language in which information conveyance through give-and-take exchange is an expected and normal aspect of ASL discourse (Graybill et al., 2008; Valli et al., 2005). Translations of English information into ASL (which must be on film, because ASL is not a written language), and even most ASL-based health information developed from scratch for deaf people, feature one individual on-screen presenting information in a monologue format. This is not the typical manner in which Deaf people prefer to acquire information, even in settings which lend themselves to monologues such as a public presentations. Considerable interaction between the speaker and the audience as information is conveyed is the sociolinguistic norm in the Deaf community. Thus, in addition to the translation problems noted earlier, conveyance of information in purely monologic format, even in otherwise fluent ASL, risks diminished comprehension among deaf viewers because it deviates both linguistically and culturally from the dialogic norm of the language and people who use it.

## Our English-to-ASL Adaptation Approach

We prefer to follow the adaptation approach, described above, that combines the beneficial features of the translation and the from scratch approaches when creating health education material for deaf audiences. In doing so, we begin with English-based source material that has been created or vetted by experts in that topic area. Two films produced at our center (Pollard & Dimeff, 2006, 2007) are adaptations of videotaped lectures regarding dialectical behavior therapy (DBT), in which the creator of DBT, Marsha Linehan, explains to the viewer (the intended being a hearing DBT patient) the nature of specific DBT skills and how to employ them (Linehan 2003; Linehan, Dimeff, Waltz & Koerner, 2000). Our center also recently completed production of five ASL adaptations of selected Web pages authored by the Centers for Disease Control and Prevention (CDC; Pollard, 2008a, 2008b, 2008c, 2008e, 2008f).[2] These ASL films are to be posted on those Web pages and thus made available to deaf viewers via the Internet, in addition to being made available as a collection on DVD. We are presently working on the adaptation of an evidence-based partner violence training curriculum (Horwitz, 2008).

We stay in close contact with the creators of the source material throughout the adaptation process that is detailed below. This helps ensure that the final product, including the ASL and, if added to the film, the English voice-over and subtitles, remain adherent to the *learning points* conveyed in the source material.

Figure 1 illustrates the main steps of our adaptation approach. After the source material has been selected, it is scrutinized to determine the learning points it contains. This step focuses on *what* is being conveyed in the source material rather than *how* it is being conveyed. The result is a list of learning points, which we record in bullet point form. For example, one learning point from our center's recent CDC adaptation project on the topic of asthma (Pollard, 2008a) involved the topic of different types of medications being used to treat asthma attack versus maintain and longer-term control of asthma symptoms. The list of bullet points is shared with the creators of the source material and revised until the creators agree that the bullet point list is accurate and complete. In most cases, we also prioritize the learning points into high-, medium-, and low-priority categories—again obtaining concurrence from the creators of the source material—so that we can remain cognizant of these priorities as we write the film scripts. For example, after consultation with the CDC, the asthma project bullet point list contained 40 high-priority learning points, 25 medium priority ones, and 14 low-priority ones. If inclusion of all the learning points would result in an undesirably lengthy film, especially in light of the content we always must add to bridge
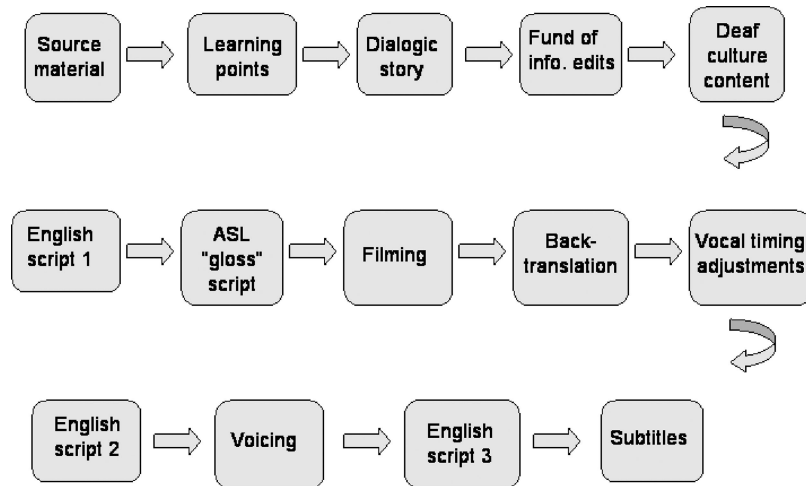
*Figure 1.* Steps in adapting source material to film for deaf audiences. ASL = American Sign Language, info. = information.

fund of information gaps, we collaborate with the source material creators to delete some of the lower priority learning points from the list.

The next step is the most creative one. We invent a story that we believe is realistic and engaging, into which the learning points will be fit. The crucial element of the invented story is that it must be one in which information can be realistically conveyed between deaf characters through dialogue. For example, in the two adapted DBT films (Pollard & Dimeff, 2006, 2007), both stories revolved around two deaf therapists who conduct DBT with deaf patients via individual and group therapy. One therapist is portrayed as new to DBT work, the other as more experienced. The learning points from Linehan's original films (which were monologues) are discussed by the deaf therapists, both through interaction with their patients and through supervision sessions between the two therapists. (See O'Hearn and Pollard, 2008, for specific illustrations and dialogue from these films.) In the project with the CDC, the stories were set in a hypothetical residential school for the deaf. Learning points culled from the CDC Web pages were conveyed through dialogue involving teachers, students, and staff at the school who are dealing with the issues addressed on the CDC Web pages (e.g., chemical spill safety).

All of the characters in our adapted films are deaf. All of the actors are deaf and native or near-native users of ASL. The characters in our films learn and share information through interaction with one another, not through interaction with hearing people. We do this purposefully so as to avoid portraying deaf people as dependent on hearing people for information. We also strive to write scripts that show deaf persons in positions of responsibility and authority and, in other ways, portray the deaf experience as a positive and affirming one.

The dialogic scripts we write use various methods to facilitate the information exchange between characters. Usually, certain characters are more knowledgeable about a given topic than others and the learning point information is shared through a dialogue sparked by some common situation they are in. This may happen, for example, through a question-and-reply method, by characters discussing a newspaper article or recent experience, or by two characters together seeking out information they need or want to obtain. Often, key learning points are addressed more than once in the same film, to provide more than one opportunity to convey and reinforce high-priority information. It can be useful for different actors to describe high-priority learning points in different ways during the film. In two of the films produced at our center (Pollard, 2003; Pollard & Dimeff, 2007), key learning points are discussed through character dialogue but also through break-away segments in which a narrator appears, further explaining or illustrating the learning point.

The script for the dialogic story also must contain information that is not contained in the source material but essential to bridge fund of information gaps common in the deaf population (O'Hearn & Pollard, 2008; Pollard, 1998). For example, in the CDC asthma project (Pollard, 2008a), we judged that the average deaf individual would not know what a dust mite is; and in one of the DBT film adaptations (Pollard & Dimeff, 2006), we determined that we needed to explain what the word *opposite* means, as this key concept in the source film does not have a sufficiently clear ASL equivalent. Many more such examples could be offered. The need to supplement the learning point list with content intended to bridge fund of information gaps is a substantial aspect of the adaptation work and requires familiarity with the deaf population so as to reasonably predict, in light of the source material, what such information gaps might be.

Once the main elements of an engaging, dialogic story based on the source material's learning points is constructed and fund of information gaps are addressed, additional content relevant to Deaf culture and the everyday lives of deaf people is added to the script. Similarly, source material content that would be irrelevant in the lives of deaf people must be omitted or modified. In our experience, making such changes increases the interest level for deaf viewers, enhances the sense of personal relevance of the material, and fosters the comprehension and retention of the learning points.

For example, in our CDC project, source material references to listening to radio broadcasts to obtain information during disasters

or other public health emergencies would not be relevant to our target deaf audience and might well have been off-putting if such content was merely translated into ASL, as if we overlooked the fact that radio is not accessible to deaf people. Instead, we omitted those radio references and created a supplemental film (Pollard, 2008d) describing procedures, publications, and state-of-the-art technology such as *reverse 9-1-1* specifically designed to bring disaster information to deaf citizens. In our DBT project, references to listening to music and other auditory experiences also needed to be omitted or altered.

Apart from the need to address problematic source material references to auditory experiences, we seek opportunities to include content in our adapted health education material that pertains to familiar experiences in deaf peoples' lives as well as opportunities to explain source material learning points in ways that are more in-tune with the deaf experience. For example, in *Opposite Action,* one of the adapted DBT films (Pollard & Dimeff, 2007), the characters discuss how to politely but assertively make requests pertinent to their Americans With Disabilities Act rights. In another segment from that film, we show how ASL efficiently and cleverly conveys the concept of *opposites* through signs that employ 180° reversals in movement without a change of sign handshape. In a project adapting written DBT material (O'Hearn & Pollard, 2008), we modified the mnemonic used to help hearing patients remember certain DBT skills. The standard mnemonic is DEAR MAN and our revised mnemonic, which still addresses the original learning points in the DBT source material, was DEAF CAN.

At this stage of the adaptation process, the first of several English scripts can be generated. ASL has no written form, so scripts first must be written in English—not only because it aids our internal communication but because we share this first English script with the creators of the source material, seeking their feedback as to whether we have properly reflected the source material learning points in the characters' dialogue. The source material collaborators usually suggest a number of edits pursuant to that goal. Reaching agreement with the source material creators on the first English script is an important early goal in the adaptation process.

However, because our adapted films are primarily for deaf audiences, they feature actors communicating with one another in ASL, not English. (An English language voice-over and subtitles are usually added at the end of the process, as shown in Figure 1.) ASL vocabulary, grammar, and syntax differ markedly from English (Valli et al., 2005). Because some deaf actors may struggle with English literacy and because translating from English to ASL in one's head during filming would be arduous and unreliable, the first English script is not used to guide the actors during filming. Rather, a script featuring ASL *gloss*[3] is developed, based on this first English script. It is this gloss script that the actors follow during filming.

After filming and rough editing are completed, project members who are bilingual in ASL and English review the film and *back-translate* the ASL dialogue into English. Because the two languages are so different, the ASL dialogue produced by the actors always differs to some degree from the specific language of the first English script. Plus, some last-minute alterations in phrasing or content always are made on the film set. The English back-translation parallels what was actually uttered in ASL. This back-

translation forms the basis for the film's English voice-over script and subtitles, assuming these elements are desired. However, before it is used for these purposes, the back-translation document is shared with the creators of the source material. This constitutes their first look at what the actors really said in ASL. Here, the creators have another opportunity to provide input, this time in regard to what will be spoken on the English soundtrack. Often, a given English wording choice of the back-translator is just one of several possible, equally accurate translations. Sometimes, the creators of the source material request slightly different wording, here and there, and such requests usually can be accommodated without sacrificing the fidelity between the ASL and the English translation.

One more step is necessary before the back-translated English script is ready for use in the voice recording studio. The voice-over phrasing must be synchronized in time with the actors' ASL phrasing. This can be challenging in light of structural differences between English and ASL. The amount of time that elapses during a given ASL utterance may be more or less than the amount of time needed to speak the translation in English. When an ASL film has an English soundtrack, it is highly desirable for the English translation to fill the same amount of time as the ASL utterance. The vocal line should begin and end at the same time as the actor's ASL movements begin and end. Failing to achieve this synchronicity impairs the aesthetics of the film and hampers comprehension when the film is being watched by a mixed group of deaf and hearing (or hard-of-hearing) viewers. Therefore, the bilingual voice talent practices watching the rough-edited film while speeding up and slowing down their delivery of the voice-over script lines as needed to match the ASL time requirements. If such timing adjustments are insufficient, the bilingual voice talent makes minor edits to the vocal script to better fit the ASL time frame. This yields a second English script that is shared with the creators of the source material, as has been described. This script, pending any input from the source material creators, then is used in the voice recording studio.

The voice-over track is then recorded and added to the film. However, minor deviations in phrasing and other last-minute edits often get made in the voice recording studio. These changes are documented, yielding a third and final English script. This script is used to generate English subtitles, so that deaf and hard-of-hearing viewers can read exactly what is said on the English soundtrack. Hard-of-hearing individuals who do not know ASL may depend entirely on the subtitles for access to the film's information. Even people who are fluent in ASL frequently like the option of reading subtitles, so they can compare the English translation to the original ASL and thus supplement the information they are getting

[3] Because ASL is not a written language, researchers and teachers have developed a method of using English words and various symbols to describe the content, syntax, and grammatical features of ASL statements. This is necessary to accurately describe critical features of ASL such as handshapes, sign movements, directions of movement, and nonmanual markers such as grammar indicators that are conveyed only by facial expressions. This written descriptive system is referred to as *gloss* and is the standard manner in which people write about ASL language samples. Gloss is not a written form of ASL per se. It is merely a convention used among teachers, researchers, and others who necessarily must discuss ASL in publications and other writings.

from one or the other of these sources. Also, comparing ASL to English subtitles is helpful in increasing many deaf individual's familiarity with English vocabulary.

The resources needed to create adapted health education materials for deaf and hard-of-hearing audiences are not exorbitant or particularly hard to find. Bilingual (ASL and English) individuals who are very familiar with the deaf experience are needed to examine the source material and develop and prioritize the learning point list. Our team includes both deaf and hearing people. These same individuals, especially if they have a flair for creativity and scriptwriting, then develop the dialogic story through which the learning points will be conveyed, including the modifications and additions needed to maximize the effectiveness and relevance of the adapted material for deaf audiences. Deaf actors are needed, of course, and we have learned that some deaf individuals are more effective in an acting role than others. ASL fluency is a must for the performers, but this does not always equate with the requisite acting skill needed. ASL-fluent acting coaches are very helpful. High-quality filming equipment and film editing resources are needed. The filming and production crews we use to make our films are not fluent in ASL nor particularly knowledgeable about deaf issues. We supplement their invaluable technical skills with consultation and sign language interpreter services where necessary. Bilingual consultants are particularly needed to assist the individual(s) who do the film editing (if they do not know sign language) because they cannot edit properly without knowing exactly what the actor is signing. When adding vocal tracks to adapted health education films, bilingual individuals with good vocal talent are essential, as they must follow the ASL film content when creating the vocal script and doing the actual voice recordings. Technical expertise and resources are needed at the end of the project to create the resulting DVD or Web-based product.

## Conclusions

The American deaf population stands to benefit greatly from the wider availability of health education material in formats that are linguistically accessible, culturally affirming and relevant, and that contain accurate, up-to-date information that has been shown to be helpful to the general (hearing) population. The procedures described above aim to yield educational material that is accessible to deaf, hard-of-hearing, and hearing people alike, containing information that has been reviewed and endorsed by the creators of carefully selected source material but adapted in ways that maximize comprehension and engagement for the intended deaf and hard-of-hearing audience. Such outcomes are consistently reported by the users of our adapted materials although empirical research demonstrating the greater efficacy of our adaptation approach in comparison to other approaches to creating effective health education material for deaf and hard-of-hearing audiences has yet to be conducted.

The reduction and prevention of health disparities in the deaf population may depend heavily on the creation and distribution of such adapted health education material. Researchers, educators, policy makers, and funders concerned with health disparities should recognize that the American deaf population is a particularly at-risk group and allocate reasonable efforts and resources to address this minority language population's health education needs.

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